STATEMENT OF FRED FRESE

ON BEHALF OF THE NATIONAL ALLIANCE FOR THE MENTALLY ILL

BEFORE THE HOUSE OF REPRESENTATIVES COMMITTEE ON VETERANS' AFFAIRS SUBCOMMITTEE ON HEALTH

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Chairman Moran, Vice Chairman Stearns, Representative Filner and members of the Subcommittee, I am Fred Frese of Akron, Ohio. I am pleased today to offer the views of the National Alliance for the Mentally Ill (NAMI) on the mental health, substance-use disorders and homeless programs within the Department of Veterans Affairs.

In addition to serving on the NAMI Board, I am a veteran myself. In 1966, I had been selected for promotion to the rank of Captain in the U.S. Marine Corps. That is when I was first diagnosed as having the brain disorder schizophrenia – perhaps the most severe and disabling mental illness diagnosis. Since my original diagnosis, I have been treated within the VA medical system, both as an inpatient at the VA hospital in Chillicothe, Ohio, and as an outpatient. Over the years, I have served on numerous advisory panels to the VA on care for the seriously mentally ill; including the VA's National Psychosis Algorithm and the VA's Consumer Liaison Committee on Care of Severely Chronically Mentally Ill Veterans Committee. I also currently serve as chair of NAMI's Board of Directors Subcommittee on Veterans Affairs.

WHO IS NAMI?

NAMI is the nation's largest national organization, 210,000 members representing persons with serious brain disorders and their families. Through our 1,200 chapters and affiliates in all 50 states, we support education, outreach, advocacy and research on behalf of persons with serious brain disorders such as schizophrenia, manic depressive illness, major depression, severe anxiety disorders and major mental illnesses affecting children.

NAMI and its veterans have established a NAMI Veterans Committee to assure close attention to veterans mental health issues not only at the national level, but also within each Veterans Integrated Service Network (VISN). The NAMI Veterans Committee includes members in each of the 22 VISNs who advocate for an improved continuum of care for veterans, active military, and dependents with severe mental illness. The membership of the NAMI Veterans Committee consists of persons with mental illness, or family and friends of a person living with a severe mental illness who have an active involvement and interest in issues impacting veterans and our military. NAMI is therefore pleased to offer our views on the programs that serve veterans with severe mental illness.

Mr. Chairman, for too long severe mental illness has been shrouded in stigma and discrimination. These illnesses have been misunderstood, feared, hidden, and often ignored by science. Only in the last decade have we seen the first real hope for people with these brain disorders through pioneering research that has uncovered both biological underpinnings for these brain disorders and treatments that work. NAMI applauds the contributions of VA schizophrenia research to the understanding and treatment of these illnesses and supports the development of the VA mental illness research infrastructure through the Mental Illness Research, Education and Clinical Centers (MIRECC).

The VHA has grown from 54 hospitals in the 1930's to 173 medical centers, 650 outpatient community and outreach clinics, and over 51,000 medical center beds with the VHA treating nearly a million patients a year in VA hospitals alone. However there is ample evidence that providing consistent and quality services to the growing number of veterans presenting for

care has become challenging due to a five–year budget freeze, a reorganization that decentralized authority, and substantial reductions in staff. As this Subcommittee knows, Public Law 104-262, the Veterans' Health Care Eligibility Reform Act mandated that the Veterans Health Administration (VHA) must maintain capacity for providing treatment and services for veterans with severe mental illness. To this date, the VHA has been unable to maintain capacity in providing the necessary services and treatment for veterans with severe and chronic mental illness.

An acceptable continuum of care should include the availability and accessibility of physician services, state of the art medications, family education and involvement, inpatient and outpatient care, residential treatment, supported housing, assertive community treatment, psychosocial rehabilitation, peer support, vocational and employment services, and integrated treatment for co-occurring mental illness and substance abuse. The services a veteran requires from this continuum of care at any given time are determined by the fluctuating needs of his or her current clinical condition and should be established in conjunction with his or her treatment team. All services should be available without waiting lists or other barriers to accessing needed treatment and services. To be a comprehensive system of care—the VHA must have the capacity to provide such services.

The VHA's 22 VISNs were instituted to administer the health services (including mental illness treatment) for VA hospitals and clinics. The idea of these VISNs was to decentralize services, increase efficiency and shift treatment from inpatient care to less costly outpatient settings. The VHA is in charge of allocating annual appropriations for each of these 22 VISNs, but does not specifically direct funds to be spent for mental illness treatment and services. Once funding is received, each VISN has authority to allocate resources to hospitals and clinics within their jurisdiction with broad autonomy. NAMI's concern is that with the flat or declining budgets in each VISN, services for veterans with severe mental illness will not receive the treatment that is needed.

Mr. Chairman, in NAMI's opinion, the lack of access to treatment and community supports for veterans with severe mental illness is the greatest unmet need of the VA. The FY 2002 Independent Budget for the VA estimates that 454,598 veterans have a service connected disability due to a mental illness. Of great concern to NAMI are the 130,211 veterans who are service connected for psychosis—104,593 of them who were treated in the VHA in FY99 for schizophrenia, one of the most disabling brain disorders. Over the last five years the VHA has shifted its focus of serving veterans with severe and chronic mental illness from inpatient treatment to community based care. In FY 1999, out of the 191,606 veterans who were treated for a severe mental illness, only 33,531 veterans received treatment in an inpatient setting. NAMI strongly supports treating veterans with severe mental illness in the community when the proper intensive community supports and treatment are available and easily accessible. However, we are very concerned that those veterans who need inpatient care are increasingly unable to access needed treatment because of the limited inpatient beds, and the dramatic shift to outpatient treatment.

NAMI is extremely grateful for the leadership Congress has provided in holding the VHA accountable for its inability to ensure that savings derived from the closure of inpatient psychiatric beds is transferred into community-based treatment services. The VHA should not be allowed to make the same mistakes that so many states and communities have made over the past quarter century with respect to deinstitutionalization. Numerous studies have

demonstrated that in states all across our nation dollars saved through the closing of state psychiatric hospitals were either never transferred into the community, or squandered on community-based services that lacked focus and accountability. From NAMI's perspective, it is obvious that this significant decrease in inpatient care has not resulted in a sufficient transfer of resources to community-based treatment and supports for veterans with severe mental illnesses.

NAMI would urge this Subcommittee to specifically direct the VHA to require that all savings from cuts in inpatient psychiatric beds be reinvested in intensive case management services for veterans with severe mental illnesses.

Mental Health Intensive Case Management

As members of this Subcommittee know, the VHA has issued a directive for Mental Health Intensive Case Management (MHICM). MHICM is based on the Substance Abuse and Mental Health Services Administration's (SAMHSA) standards for assertive community treatment (ACT), which NAMI believes are proven, evidence-based approaches in treating the most severe and persistent mental illnesses. FY 1998 Compensation and Pension data show that almost 40,000 veterans with severe mental illness are in need of intensive community case management services. Further VHA data shows that assertive community treatment is cost-effective as well as effective in treating severe mental illness.

However, a 1998 survey by the Committee on Care of Severely Chronically Mentally Ill (SMI) Veterans Committee demonstrated that just over 8,000 veterans have been receiving some form of intensive case management, and that only 2,000 veterans are enrolled in treatment programs that meet the SAMHSA standards. The SMI committee also reports that intensive case management teams are operating at minimal staffing and some are facing further staff reductions. NAMI strongly recommends that Congress appropriate the funds necessary to provide the essential number of new intensive case management teams and to fully staff existing teams so that our nation's most vulnerable veterans receive appropriate and coordinated care.

Community-Based Outpatient Clinics

The VHA has expanded the use of Community Based Outpatient Clinics (CBOCs) as primary care clinics. Many of the CBOCs were instituted in areas where VA health services were not easily accessible allowing many more veterans access to needed health care. However, the SMI committee reports that out of the 350 CBOCs operated, only 40% of these facilities offer treatment services for veterans with severe mental illness. NAMI is truly concerned that meaningful community-based capacity is not being developed to treat chronically mentally ill veterans in their communities; and agrees with the recommendation of the Committee on Care of Severely Chronically Mentally Ill (SCMI) Veterans committee for a $40 million dollar enhancement to mental health capacity to give the VHA options in bettering care and treatment for veterans with acute needs.

Access to Appropriate Medications

NAMI would also urge the Subcommittee to continue to monitor proposals to implement restrictive drug formularies in VISNs that cover psychotropic medications. The NAMI

Veterans' Committee continues to hear reports of veterans with mental illness not getting access to the newest and most effective atypical anti-psychotic medications. Specifically, our members tell us about VISNs imposing limited formularies that require veterans to fail first on older medications, or in extreme cases, include only a single medication within an entire classification of drugs for major disorders such as schizophrenia and depression. The SMI committee reports that currently 17% of the VA's total pharmacy budget are being spent on psychotropic medications. At the same time there appears to be wide variance in the use of the newest and most effective medications that have been proven effective in treating schizophrenia. NAMI feels strongly that veterans with mental illness deserve full access to the newest and most effective medications.

NAMI also has deep concerns regarding deliberations taking place within the Department of Veterans Affairs concerning a proposed treatment guideline for veterans with schizophrenia. Specifically, NAMI strongly objects to any treatment directive that would interfere with the clinician's choice of the best medication for each patient, based on that individual patient's clinical needs. While cost is an appropriate consideration, it should be only one factor in medication choice and must not be allowed to be the primary consideration in choosing a medication to treat severe mental illness.

There is overwhelming peer-reviewed research establishing that atypical antipsychotic agents are the treatments of choice for schizophrenia. This evidence has informed the development of a number of guidelines for the treatment of schizophrenia, including the Texas Medication Algorithm Project and the Expert Consensus Guideline Series. Despite these guidelines, Veterans Administration pharmacy managers have occasionally proposed cost-cutting plans that would have required veterans to "fail first" on a conventional antipsychotic before being treated with an atypical antipsychotic. Such a policy would have bordered on the unethical, since for some veterans, atypicals are more effective against negative symptoms of schizophrenia and produce better outcomes, and since atypicals are far less likely to result in tardive dyskinesia, a devastating movement disorder. We were delighted that the Veterans Administration has not pursued this irresponsible cost-cutting approach.

Mr. Chairman, NAMI recently began receiving reports about an equally disturbing cost-cutting proposal at the VA. According to a presentation made by a VA Psychiatrist at a VA Schizophrenia Conference in Maryland on March 29 2001, the Department of Veterans Affairs is considering guidelines that will *reduce* treatment options for veterans struggling with devastating mental illnesses and restrict the discretion of VA staff psychiatrists. This new proposal, as NAMI understands it, would establish a "fail-first" policy among the atypical antipsychotics, not in response to published guidelines or best practices or to the needs of individual veterans, but rather in response to a cost-cutting mandate.

The fundamental issue is the role pharmacy costs should play in choosing among alternative treatments that are not equivalent. There are numerous studies demonstrating that these pharmacy costs are only a small part of the cost of schizophrenia care that can include hospitalization, residential care, supportive services, etc. Pharmacy savings that are achieved through restrictive formularies are often offset by increased clinical care costs elsewhere. Such studies do suggest the importance of looking at the costs of the entire care system for an illness rather than trying to control costs in just one area.

In NAMI's view, the focus should be placed on clinical decision-making in the Veterans Administration. The NAMI Veterans' Committee is dedicated to the idea that each individual veteran has different treatment needs, and that ultimately the doctor and patient must make clinical choices based on the needs of that particular patient.

Because patients differ in their clinical responses to different drugs, in their sensitivity to specific side effects, and in their tolerance for these side effects when they occur – and because the atypical antipsychotic agents are different from one another in their clinical effects for a particular patient and in their side effects – the proposed "fail-first" requirement cannot represent best clinical care. None of the published guidelines establish preferred agents among the atypicals (other than clozapine) – they leave the choice to the clinician, based on the patient's needs. A "fail-first" requirement substitutes the judgment of pharmacy managers who have never seen the patient for the judgment of the patient's own doctor.

Certainly **if** a medication on average results in lower total cost of treatment, and **if** there is no clinical reason to prefer a different medication for a particular patient, that medication would be a reasonable first choice for the clinician. However, in practice, there are often reasons for preferring a different medication. It is important that the Veterans Administration leadership emphasize the decisive role of clinical judgment in the choice of medications, to guard against overzealous pharmacy management.

Congress has funded a National Institute of Mental Health (NIMH) project on Clinical Antipsychotic Trials of Intervention Effectiveness, known as the CATIE project. This study is designed to provide critical information about the relative benefits, side effects, and costs of different atypical antipsychotic medications. This study should provide the necessary data to make reasonable, informed choices based on a range of evidence – data that do not currently exist. In the absence of such data, considerable latitude should be given to each clinician to select the best medication based on the needs of a specific patient.

Veterans with schizophrenia and their families expect nothing less that the highest quality medical care. Therefore, NAMI specifically urges the Department of Veterans' Affairs to reject "fail-first" guidelines that inherently restrict the doctor's ability to choose the best medication for his or her individual patient.

A January 2001 GAO report concluded that the VA was not providing sufficient oversight in ensuring that all VISNs are in compliance with the national formulary. Further, NAMI agrees with the GAO's recommendation that in order to ensure more effective management of the national formulary, the Secretary should:

(1) direct the Under Secretary for Health to establish a mechanism to ensure that VISN directors comply with national formulary policy.
(2) require the Under Secretary for Health to establish criteria that VISNs should use to determine the appropriateness of adding drugs to supplement the national formulary and monitor the VISNs application of these criteria.
(3) direct the Under Secretary for Health to establish a non-formulary drug approval process for medical centers that ensures appropriate and timely decisions and provides that veterans for whom a non-formulary drug has been approved will have continued access to that drug, when appropriate, across VA's health care system.

(4) direct the Under Secretary for Health to enforce existing requirements that VISNs collect and analyze the data needed to determine that non-formulary drug approval processes are implemented appropriately and effectively in their medical centers, including tracking both approved and denied requests.

Consumer Councils

The Fourth Annual Report to the Under Secretary for Health submitted by the Committee on Care of Severely Chronically Mentally Ill Veterans dated February 1, 2000 stated in recommendation 9.1: "Networks should redouble their efforts to establish mental health stakeholders councils at all VHA facilities and at the Network level. Progress in establishment of such councils should be monitored and considered in the evaluation of key officials."

NAMI fully supports the implementation of Mental Health Consumer Councils and the recommendation by the SMI committee. At the VISN level, Mental Health Consumer Council brings together consumers, family members, Veterans Service Organizations, and community agencies that can discuss services, policies, and issues which are important to veterans receiving treatment for mental illness. Approximately half of the VISNs have Mental Health Consumer Councils but full participation by all VISNs is still needed.

Staff Education

As you have heard at this hearing, the Department of Veterans Affairs has dramatically shifted its mental health service delivery from traditional, hospital-based services to outpatient and community-based rehabilitative approaches. The adoption of newer recovery-based psychiatric rehabilitation practices requires a significant paradigm shift for service providers. It requires the learning of new skills, some of which are contrary to their former professional training.

The VA has made minimal investment in the re-training of staff in conjunction with re-engineering its mental health services. For VA to successfully provide state-of-the-art services for veterans with severe mental illness, funding should be immediately targeted for this purpose. The VA should also sponsor a series of educational initiatives designed to re-train direct-care Mental Health staff in state-of-the-art psychiatric rehabilitation principles and practices, as well as to ensure these staff can actively participate in networking with other professional family and consumer advocacy organizations.

Homeless Veterans

NAMI applauds the Subcommittee's efforts to expand services for homeless veterans. NAMI would also like to thank Congressman Lane Evans for introducing HR 936, the Heather French Henry Homeless Veterans Assistance Act and recognize Vice-Chairman Stearns for his co-sponsorship. This bipartisan legislation would establish a goal of ending homelessness among veterans and encourage all federal, state and local governments, private and

community agencies to work together towards the goal of eradicating homelessness among our nations veterans within the next decade.

As you know, severe mental illness and co-occurring substance abuse problems contribute significantly to homelessness among veterans. Studies have shown that nearly one-third (approximately 250,000) of homeless individuals have served in our country's armed services. Moreover, approximately 43% of homeless veterans have a diagnosis of severe and persistent mental illness, and 69% have a substance abuse disorder. NAMI strongly supports provisions in the bill that would mandate evaluation and reporting of mental illness programs in the VA and that veterans receiving care and treatment for severe mental illness be designated as "complex care" within the Veterans Equitable Resource Allocation system. Moreover, NAMI feels that language providing for two treatment trials on the effectiveness of integrated mental health service delivery models would be very beneficial in identifying best practice in serving and treating veterans with severe and persistent mental illness within the VA.

Mr. Chairman, NAMI strongly supports the Heather French Henry Homeless Veterans Assistance Act and urges you and your colleagues on the Veterans' Affairs committee to support this legislation which would help end homelessness for veterans and help meet the needs of veterans with severe mental illness. Our nations veterans with severe mental illness should be in treatment and not on the street.

Co-Occurring Disorders

National studies commissioned by the federal government estimate that 10 – 12 million Americans have co-occurring mental and addictive disorders. The prevailing research confirms that integrated treatment for co-occurring disorders is much more effective than attempting to treat these illnesses separately. Integrated treatment means mental illness and addictive disorders services and interventions are delivered simultaneously at the same treatment site, ideally with cross-trained staff. What is not considered integrated treatment is sequential treatment (treat one disorder first, then the other) or parallel treatment (in which two different treatment providers at separate locations use separate treatment plans to treat each condition separately but at the same time).

NAMI supports the research being done in the MIRECCs to improve the health services for patients who have co-occurring mental and addictive disorders. The VISN 1 MIRECC has concluded that emphasis should be placed on integrated treatment, and that attention to a veteran's multiple disorders produces better outcomes. The VA needs to continue to develop innovative programs and appropriately train staff to help veterans living with a severe mental illness and an addictive disorder.

Research

Even though the VA has made genuine progress in recent years in funding for psychiatric research at the VA, such research remains disproportionate to the utilization of mental illness treatment services by veterans. Veterans with mental illness account for approximately 25% of all veterans receiving treatment within the VA system. Despite this fact, VA resources devoted to research has lagged far behind those dedicated to other disorders. In 1998, only

11% of all research at the VA was dedicated to chronic mental illness, substance abuse and PTSD. This level has remained unchanged for the last 15 years, despite the fact the 22% of patients in the VA system receive mental illness treatment.

For FY 2002, NAMI has urged the Appropriations Subcommittee on VA, HUD, and IA to support the recommendation of the *Independent Budget* to increase the overall VA research budget by $45 million. More importantly, NAMI urges that $30 million of this increase go toward severe mental illness research. This increase would double mental illness research within the VA, an amount that has remained flat over the past 15 years. Research is one of the VA's top missions and NAMI is pleased that the VHA is taking steps to increase the number of Mental Illness Research, Education and Clinical Center (MIRECCs), centers designed to serve as infrastructure support for mental illness research. Because medical research is so important to improved treatments for severe mental illnesses and ultimately the cure of these disabling brain disorders, NAMI recommends full funding of the MIRECCs.

Our nation's dedicated veterans deserve the best care and treatment, including access to the highest quality services and state-of-the-art medications. Thank you for the opportunity to share NAMI's views on this important matter.

Fred Frese was a 25-year old Marine Corps captain when he had his first psychotic break and was diagnosed with paranoid schizophrenia. Although repeatedly hospitalized during the next decade, he completed graduate work in both management and psychology, earning a doctorate in psychology in 1978. Since then, he has continued to work in clinical and administrative positions with the Ohio Department of Mental Health. For 15 years until his retirement in 1995, he served as Director of Psychology at Western Reserve Psychiatric Hospital, a state-operated facility in the Cleveland-Akron area.

A member of the National Alliance for the Mentally Ill (NAMI) since 1989, Dr. Frese is currently the First Vice President of its National Board. He currently serves on the Board of the Summit County Alliance for the Mentally Ill.

Dr. Frese has given more than 300 presentations on topics related to serious mental illness in 30 states, Canada, Puerto Rico, and Washington, D.C. He has published extensively, and has been on the advisory reviewing boards of five professional journals, including Schizophrenia Bulletin. Along with his wife, Penny, he has also co-produced a widely distributed training video about coping with schizophrenia.

Dr. Frese has been a faculty member at Case Western Reserve University, Kent State, Ohio University, and Ashland Theological Seminary. He has also served as Chairperson of the Akron Area Mental Health Board. Dr. Frese was the founder and first president of Community and State Hospital Psychologists, the American Psychological Association's division for psychologists serving persons with serious mental illness. He also was on the Board of Trustees of the Ohio Psychological Association, where he served as Chair of the committee for the Mentally Ill Homeless. Additionally, he served as president of the National Mental Health Consumers' Association.

Dr. Frese served as a consultant to the Department of Veterans Affairs on a project to improve clinical practice. He has testified before congressional committees on priorities for public mental health services and is a part of the American Psychological Association Task Force for the Seriously Mentally Ill/Seriously Emotionally Disturbed. He and his wife and their four children live in the Cleveland-Akron area of Ohio.

NAMI—the National Alliance for the Mentally Ill is not in receipt of any federal grant or contract relevant to the subject matter of this testimony